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Lihua Dishman

A. T. Still University of Health Sciences, ldishman@atsu.edu

Vicki Schroeder

V.S.E. (Vision*Strategy*Execution) Healthcare Consulting, LLC, vvschroed@gmail.com

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A COVID-19 patient's experience: Engagement in disease management, interactions with care teams and implications on health policies and managerial practices

Lihua Dishman, *A. T. Still University of Health Sciences, ldishman@atsu.edu*

Vicki Schroeder, *V.S.E. (Vision*Strategy*Execution) Healthcare Consulting, LLC vscbroed@gmail.com*

Abstract

This narrative inquiry aimed to explore a COVID-19 patient's lived experience from contracting the disease to recovery and understand the implications of this unique patient experience on health policies and managerial practices. The personal narrative approach was used to chronicle the patient's weekly journey in disease management. Best practices emerged from her and her family members' engagement in managing COVID-19, and interactions with her primary care provider and COVID-19 Response Team. Her COVID-19 patient experience also provided a basis for implications on public health and healthcare policies and managerial practices. Three key dimensions were perceived to have positively impacted the COVID-19 patient's experience and health outcomes: information seeking, communication, and self-awareness. Physical, mental and emotional support from family members were also perceived to have a positive impact on the patient's experience and outcomes. Three key dimensions were perceived to have negatively impacted the COVID-19 patient's experience and health outcomes: federal government's lack of coordination in crisis management, CDC's slow actions in disease control and prevention and primary care provider's absence in care continuity. Patients must take active ownership and engage consistently in their disease management, which could help improve their own experiences and overall health outcomes. Proactive engagement in care and in making treatment decisions may improve disease outcomes even when coordinated responses to health crises were lacking in the country and care continuity by providers was absent. Interactions with care providers also present opportunities for patients to help providers improve their practices. Patients are integral members of care teams.

Keywords

COVID-19, patient experience, patient-provider interactions, continuity of care, patient and family engagement, policy implications, managerial implications

Introduction

According to the Centers for Disease Control and Prevention, COVID-19 stands for corona virus disease, and was also called 2019 novel coronavirus or 2019-nCoV earlier.¹ The World Health Organization (WHO) described COVID-19 as an infectious disease caused by the coronavirus newly discovered in 2019 and stated that most COVID-19 patients would experience mild to moderate respiratory illness and would not need any special treatments to recover.² The WHO declared the outbreak of the 2019 novel coronavirus as a Public Health Emergency of International Concern on January 30, 2020, and then COVID-2019 as a global pandemic on March 11, 2020 because the disease's spread and severity had reached alarming levels but met by alarming levels of governmental inaction.³⁻⁴

Among the six dimensions of patient experience in an outpatient context, participative care of providers, courtesy of facilities' staff, patient self-reported sickness and staff

follow-up were powerful predictors of overall positive patient experience.⁵ Hospital patients' education level was one of the two factors that most significantly predicted a positive patient experience.⁶ Continuity of care is another factor that contributed to positive patient experience and was beneficial for improving health outcomes of patients.⁷ Top-performing hospitals ensured care continuity by providing patients and families with clear discharge instructions when discharging patients, followed by telephone check-ins with high-risk patients.⁸ Engaging patients as partners in care contributed to improved quality of patient care.⁹ Providing best patient care at lower cost would rely on a supportive framework of health policies.¹⁰

Nevertheless, extant empirical literature is scant as it pertains to understanding the unique experiences of patients who contracted the novel coronavirus (or COVID-19), as well as factors such as patient and family engagement in disease management and interactions with care teams that have contributed to positive or negative

patient experience. Therefore, this narrative inquiry was timely and necessary. It aimed to explore a COVID-19 patient's lived experience from contracting the disease to recovery and to understand the implications of this unique patient experience on health policies and managerial practices. It sought to answer a research question: what is the unique experience of a COVID-19 patient in the United States? Study findings may provide some insights for health policymakers and administrators, healthcare providers and patients and their families.

Methods

This section will focus on three contextual areas. The first is an explanation of what the narrative inquiry approach is and why it is applicable to this study. The second is a description of how the narrative inquiry approach is applied to this study. Finally, the third is a discussion of the limitations associated with applying the narrative inquiry approach.

Narrative Inquiry

The narrative inquiry approach can be used for interpreting personal narratives or stories to understand and illuminate the lives of individuals who created them.¹¹ These narratives or stories may also reveal the world in which these individuals lived. Moreover, such a research design helped facilitate a more in-depth exploration of individual lived experiences and interpretation of the collected textual data in narratives.¹²

In this qualitative inquiry, personal narratives were used to chronicle a patient's five-week journey from contracting the novel coronavirus (or COVID-19) to a slow recovery. The patient's personal story provided a basis for understanding her and her family members' engagement in managing COVID-19, and interactions with her primary care provider and COVID-19 Response Team. Furthermore, her story helped illuminate the gaps and inconsistencies in the current policies for managing public health crises at the United States federal, state and local levels and lack of adequate action plans for managing such crises. Her story also shed a light on the need for improving healthcare managerial practices.

Limitations of Applying Narrative Inquiry

It is important to point out the potential limitations of this narrative inquiry. First, the personal narratives may reflect biases associated with Vicki's personal, professional, and academic background. Second, the interpretations of the personal narratives may reflect the collective biases of both researchers because of their personal beliefs, professional views and political stances.

Results

Vicki lives in a Western Michigan city along the shore of Lake Michigan. The city and its surrounding areas comprise a metropolitan area with over 150,000 residents. A multinational corporation calls the area home with several campuses. Sharing her spacious three-story house with her husband and college-bound daughter, Vicki runs her healthcare consulting business from her home office, advising community members regarding healthcare matters, volunteers at local food bank weekly and organizes community advocacy activities.

She had a mild cold in early through middle of February 2020. When she felt better in late February, she interacted with the public in several highly stressful events. For example, one was the publicity and production of a play, *The Gun Show*; and the other was the discussion and coordination of building and developing Tiny Houses for Big Change, which is a project to help community members suffering from homelessness in order to improve health equity and population health.

The following chronicles her lived experiences of contracting and then recovering from COVID-19 from late February to early April. The week numbers below are based on her experience as a COVID-19 patient, not on the basis of our weekly calendar.

Week 1: February 29 through March 6

On February 29 (Saturday), she was out and about running errands during the day, and then her body temperature spiked to 103°F in the evening when she was at home. After taking some over-the-counter fever reduction medication, her body temperature slightly went down to 102.5°F. Over the next five days (March 1 to March 5), her fever remained, hovering around 102.5°F-103°F. In addition to fever, she experienced aches, headaches, fatigue, taste loss, extreme cough, and shortness of breath. As the days progressed, her fatigue, shortness of breath, and extreme cough intensified.

She initially suspected influenza, although there were differences between her symptoms and typical symptoms of influenza, particularly in fatigue, extreme cough, and shortness of breath. Moreover, she had not experienced fevers that would not be reduced with medication, and her cough became so extreme that she felt a tear in her abdominal muscle, which was not present prior to the extreme cough. Having had pneumonia in the past, she felt her experiencing shortness of breath like having pneumonia when something in her lungs was limiting their capacity.

During this first week, after her fever started, she was unable to get out of bed because of her increased fatigue or talk much because of her more severe cough. She tried

a couple of cough suppressants but no success. On March 6 (Friday), the abdomen pain and extreme cough brought her to see her primary care provider, whose practice was over two hours away by car. She was so weak physically that her husband had to drive her to see the provider. The provider masked her at that point, although Vicki could not identify any foreign contacts. Symptoms at this early phase were not clear to either Vicki or the provider whether her disease was influenza or COVID-19. Testing kits for COVID-19 were not available then. The provider wrote Vicki orders for the ER should her conditions change and then sent her home. She stayed in self isolation on the ground floor while her husband stayed on the first floor.

Week 2: March 7 through March 13

She spent her second week primarily in bed. While her fever had subsided, extreme fatigue and cough became even worse. She was still healing from the abdomen pulled muscle, so any cough was painful. She tried her best to protect the muscle. The cough was not productive. The shortness of breath and cough together also resulted in wheezing. She continued to experience aches, headaches, fatigue, taste loss, extreme cough and shortness of breath.

On March 9 (Monday), she had a virtual follow-up with her primary care provider since her symptoms were not improving even slightly. In an email to her provider, she described and summarized all her symptoms and the duration and progress of the symptoms, which aligned with those of COVID-19 as the CDC communicated. At that time, Vicki and the provider had better clarity regarding the symptoms of COVID-19.

After this virtual review, the provider's office called her on March 10 (Tuesday) and referred her to the COVID-19 Response Team (CRT) of the university's health system. On March 13 (Friday), the CRT staff assessed her over the phone, reviewing all symptoms, dates, progress, and public contacts. This assessment was specific and extensive. She was on the phone with the CRT staff for about 45 minutes. The CRT determined that she had contracted COVID-19 but could not test her because she did not meet the prevailing testing criteria. At that time, testing kits for COVID-19 were considerably lacking; testing was only available to those who were admitted to hospitals, and she did not meet the criteria to be admitted to a hospital.

During this week, her daughter also returned home after the college ended campus-based classes and moved all classes online. The daughter took the vacant third floor. Although not planned, Vicki's three-story house worked well for her family, allowing each member to use one floor as she grappled with her COVID-19 situation.

Week 3: March 14 through March 20

After spending nearly three weeks in bed, she felt better towards the end of Week 3. Seeing some improvements in her condition, she decided to venture out of her house for a walk when the weather improved. Her cough was still extreme, although cough drops helped. In hindsight, she realized that she did too much too soon, because she was still very weak. For this one day of being more physically active, she lost three days of recovery and was back to part time in bed resting. During this week, she continued to experience fatigue, taste loss, extreme cough, and shortness of breath, but aches and headaches were infrequent.

Throughout this third week, it was encouraging that she was gradually feeling and seeing some improvement. Later in the week, she was able to work in the mornings.

Week 4: March 21 through March 27

The one active day in late Week 3 prolonged her recovery. Throughout this fourth week, her symptoms of aches, headaches, fatigue, taste loss, extreme cough and shortness of breath were further improving. However, this was the most difficult week, because she observed little improvements in her physical conditions, and because emotionally she was really scared and wondering whether she would ever improve. As a result, she was still primarily resting and did not have that much energy to get any work done.

Vicki was feeling scared because she contracted Guillain Barre Syndrome as a teenager. Guillain-Barre Syndrome is a rare disorder, and with this viral disease, a contracted person's immune system attacks the nervous system.¹³ She remembered that the virus could reach a person's lungs forcing the use of a ventilator and causing death. Then, the Syndrome had some medical interventions but no cure, much like COVID-19 now. The similarities between Guillain Barre Syndrome and COVID-19 were prevalent in her mind: the breathing difficulties, the aches, the overall weakness, the inability to be physically active, the slow recovery, etc. This week, she was worried, wondering if there would be only interventions but no cure for COVID-19 and hoping that her body would turn the course to health without a cure.

Week 5: March 28 through April 3

Although still feeling tired all the time and coughing at times, she was checking on her family members and friends in Week 5. Lihua was one of those friends, receiving a "Checking on You" email from her. They had a meaningful exchange of emails and decided to speak on the telephone when she became stronger. Overall, through her experience being a COVID-19 patient, she described the virus as "The Beast," echoing the experiences of many other COVID-19 patients.

Key Findings

Several main findings emerged from Vicki's personal narratives. Specifically, three key dimensions were perceived to have positively impacted the COVID-19 patient's experience and health outcomes: information seeking, communication, and self-awareness. Physical, mental and emotional support from family members were also perceived to have a positive impact on the patient's experience and outcomes.

In contrast, three key dimensions were perceived to have negatively impacted the COVID-19 patient's experience and health outcomes. The first dimension was the federal government's lack of coordinative efforts in managing the emerging public health crises and lack of clear communication about the novel coronavirus, its spread, its prevention and its treatment. The second dimension was the U.S. CDC's slow actions in providing critical information about the novel coronavirus. Finally, the third dimension was the primary care provider's absence in delivering continuity of care.

Discussion

Engagement of patient and family members in disease management

Throughout her experience as a COVID-19 patient, Vicki was always proactive, taking ownership and a leadership role in every aspect of her disease management. Her husband was fully engaged as well, helping her whenever she needed, while managing his own professional responsibilities. Her daughter was doing best by taking online courses at home, in isolation on one floor of their house.

The patient's engagement in disease management

Specifically, Vicki engaged in her management of COVID-19 in three main dimensions. The first dimension is information seeking. As a lifelong learner, healthcare advisor and higher learning educator, she apprised herself of the knowledge surrounding COVID-19 by reading information published on reliable and respected websites such as those of the WHO, CDC, Mayo Clinic and *New England Journal of Medicine*. Her health literacy about COVID-19 enabled her to be an evidence-based decision maker, as well as helped her monitor her symptoms daily and the duration and progress of these symptoms over time.

The second dimension is communication. She maintained an open communication channel with her primary care provider. For example, post office visit, she initiated a virtual follow-up with her provider after observing no improvements in her symptoms for days. She wrote a detailed email narrating her symptoms as well as their duration and progress. This detailed narrative provided a basis for her provider to diagnose her disease remotely.

With this diagnosis, her provider was able to advance her case to the university health system's COVID-19 Response Team, which confirmed her COVID-19 case after conducting an exhausting assessment with her over the telephone. This confirmation was critical in informing Vicki and her family of proper measures in self isolation to prevent further spread of the virus.

Finally, the third dimension is self-awareness. She went out of her house for a walk because she wanted to get some sun and fresh air and gain some physical strength after spending nearly three weeks in bed resting. To her surprise, this mild physical activity resulted in physical and mental exhaustion. Being aware of herself, she ceased mild physical activities and resumed bed resting. Although this one-day of mild physical activity prolonged her recovery by three days, continuing mild physical activities would have resulted in an even longer recovery time.

The family members' engagement in disease management

Vicki's husband was an IT administrator for a leading research university in the country. That university shut down its campuses in the middle of March to prevent the spread of the novel coronavirus and then was on the fly moving its thousands of courses online. He worked days and nights helping course instructors make the transition from campus-based residential courses to online courses. His job already kept him informed of COVID-19. After Vicki fell ill in late February, he was slightly under the weather, but his symptoms did not develop further. He was the driver when she was too weak to drive to the primary care provider's office over two hours away. He was the cheerleader when she was worried about her recovery, feeling emotionally exhausted. He was also the calming agent when she wanted to do more than just rest in bed.

Vicki's daughter was attending a college in Michigan. The college also shut down its campuses in the middle of March and moved its courses online. Her daughter then returned home, doing well while taking courses online, because she knew the best way to help mom recover was to be an excellent learner by studying hard. The daughter was Vicki's important emotional supporter, by taking away Vicki's worries about her transition from campus learning with friends to virtual learning at home alone as well as overall physical and emotional well-being.

Interactions between Patient and Care Providers

Several areas that are worth applauding or need improvement emerged from Vicki's interactions with her primary care provider and the COVID-19 Response Team. Quarantining at home by many people as a result of COVID-19 gave the swift rise of virtual interactions between patients and their care providers. Her interactions with her care providers included an office visit with her

primary care provider, a virtual follow-up with this provider via email and a remote assessment of COVID-19 with the COVID-19 Response Team via telephone.

Patient's interactions with the primary care provider

Vicki's primary care provider was affiliated with a large health system, which was a part of a prominent university. This affiliation was critical, because it allowed the provider to advance her case to the health system's COVID-19 Response Team right after the provider's team thoroughly reviewed the detailed symptoms and their duration and progress as narrated in her follow-up email. From this perspective, her virtual interactions with her provider were positive, and probably resulted in better outcomes for her and her family, because the CRT's COVID-19 diagnosis informed their preventive measures in self isolation at home from one another.

Nevertheless, her provider did not follow up with her via a telephone call or an email after her office visit, even though the provider gave her a mask to wear for preventing the spread of the virus. The continuity of care was absent. Had she not initiated a virtual follow-up with the provider that eventually resulted in a diagnosis of her COVID-19, her subsequent health outcomes would have been hard to imagine, most likely not as good as her current state.

Care continuity through telephone check-ins and email follow-ups is critical to people living far away from their healthcare providers, particularly during the pandemic. Although it was by choice that Vicki's primary care provider was two hours away by car, some people living in rural areas may have no choice but travel distance to see their primary care providers. Vicki did not have transportation issues, but some rural residents may not have ready transportation means to reach their primary care providers. Therefore, providing continuity of care via email or telephone may help address the inequity in our healthcare delivery system.

Patient's interactions with the covid-19 response team

The university's health system established its COVID-19 Response Team in response to the global pandemic. Vicki's telephone meeting with the CRT was productive. During this 45-minute meeting, the CRT's assessment of her symptoms and their duration and progress was exhaustive. Although feeling tired after the meeting, she knew its importance in diagnosing her disease, and perceived the CRT staff as professional and competent and her interactions with the CRT staff as positive.

However, it took three days from the day she was referred to the CRT by her provider to the day she met with the CRT via the telephone for a COVID-19 assessment. Despite her positive interactions with the CRT staff, the

three days could have made the difference between life and death for her as a confirmed COVID-19 patient.

Policy and Managerial Implications

Several implications on health policies and managerial practices emerged from Vicki's experience as a COVID-19 patient. It is important to note, she had been an executive in healthcare organizations for decades and a higher learning educator for years. She was educated and well informed. Her COVID-19 patient experience implied the absence or missing links in certain health policies and managerial practices applicable to all Americans.

Implications on health policies

The United States responded to the novel coronavirus health emergency slowly. Vicki was so sick on March 6 when she visited her primary care provider's office. As a result of the CDC's slow updates regarding the symptoms of the novel virus, her symptoms did not meet the prevailing criteria for testing, because the testing criteria were based on CDC's published information. At that time, authoritative and respected scientific sources such as the New England Journal of Medicine were already providing to the public free of charge more updated information regarding the symptoms of the novel virus. Because of our federal government's lack of coordination in crisis management and inconsistencies in communicating COVID-19, all the primary care provider did was send her home with a mask and written orders to visit ER if she needed.

The United States also did not have a coordinated effort in responding to the COVID-19 global pandemic. Confusion was abundant when it came to figuring out who was in charge of the emergency responses. For example, in a state of leadership vacuum, the federal government was disseminating confusing information regarding the availability of testing kits. As a result, testing kits were not available, and Vicki could not get a test even after the CRT confirmed her COVID-19 case.

Implications on healthcare managerial practices

Vicki's primary care provider's office did not provide appropriate continuity of care. After she was sent home with a mask and written orders to visit ER when she needed, the office never followed up with her and could have done so easily because the communication could be online via emails. Visiting the ER during this health crisis did not seem to be appropriate, since she could infect others in the ER and vice versa.

The COVID-19 Response Team did not have adequate resources. It took the CRT three days to finally meet with Vicki via telephone for a COVID-19 assessment after her primary care provider's office referred her to the CRT. This delay most likely was not the fault of the CRT, which was already working around the clock. Rather, the delay

shined a light on the cracks in the extant healthcare system and structure of this nation.

Concluding Comments

Patients must take active ownership and engage consistently in their disease management, which could help improve their own experiences and overall health outcomes. Proactive engagement in care and in making treatment decisions may improve disease outcomes even when coordinated responses to health crises are lacking and care continuity by providers is absent. Interactions with care providers also present opportunities for patients to help providers improve their practices. Patients are integral members of care teams.

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